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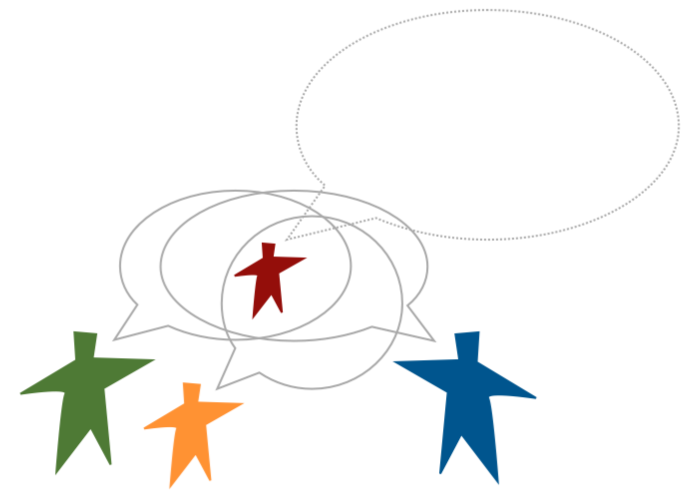
Participatory autism research



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- “Some of us aren’t meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it.” (Lowell, 1999).

A growing understanding

- Obtaining the views of disabled people – requirement of policy / legislation both nationally and internationally (UN, 2006).
- Lack of involvement and representation in organisations 'for' autistic people.
- Conflict between growing autistic voice and the discourse of dysfunction, deficiency, and dependency.
- A Future Shaped Together (Pellicano et al. 2013).
- The Shaping Autism Research UK project.

Nothing about us, without us

- Having an autonomous voice – an essential requirement for individual well-being.
- For people on the autism spectrum however, there can be a number of barriers to participation in wider social life.
- People on the autism spectrum have often been excluded from contributing towards the decisions that directly affect their own lives.
- This has led many autistic-led advocacy groups to rally behind the slogan: ‘Nothing about us, without us’.

Aspects of social participation

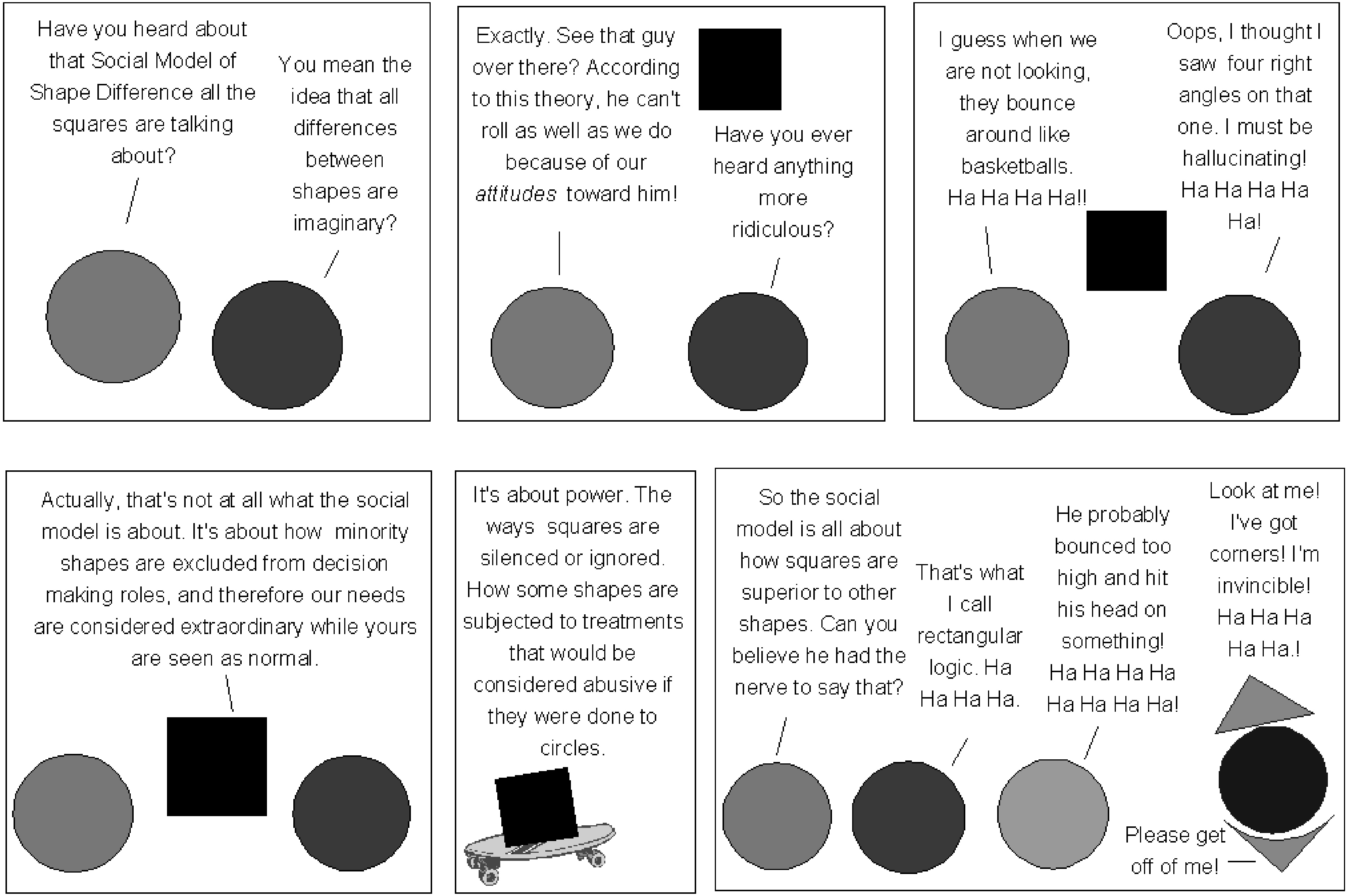
- Acceptance and understanding – a sense of belonging.
- Engagement in public and political life – being able to express oneself and affect change.
- Individual and collective concerns.
- Present lived realities – a more collaborative future?

Arnstein (1969)

Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

Aims and objectives – controversies in the field

- Models of disability.
- Normativity or the acceptance/celebration of diversity?
- Behavioural outcomes and ‘social skills’ or understanding and autonomy?
- Baggs (2012) - communication page.
- Positivist RCTs and/or building collaborative communities of practice (Wenger, 1998).



Square Talk Asperger Square 8

The concept of neurodiversity

- Variations in neurological development as part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one’s deviation from statistical or idealised norms of embodiment or observed behaviour.
- This is not to say that those who identify as autistic people or other forms of neuro-identity do not find life challenging. Autistic people are significantly disadvantaged in many aspects of life.

AET consultation data

Stakeholder group	**Understanding the individual pupil**	**Building relationships**	**Curriculum and learning**	**Enabling environments**
Practitioners	**<u>Staff training</u>**	Involving and supporting parents	Differentiated curriculum (social skills)	Quiet and safe spaces
Parents	Staff training and understanding the individual	**<u>Communication between staff and parents</u>**	Individually tailored curriculum	Structure and routine
Children and young people	Understanding from staff	**<u>Bullying (including 'friends')</u>**	Subject content and delivery	Crowds and personal space
Common ground	Staff training needed	Better communication needed and understanding	Differentiation / tailored curriculum	Structured break times and safety
Tensions	Potentially what staff are trained in	Communication not being good enough and a lack of understanding	Social skills training	Differences in view regarding how environments should be managed

Mutual incomprehension

- “95% of people don’t understand me”.
- “Friends are overwhelming”.
- “Adults never leave me alone”.
- “Adults don’t stop bullying me”.
- Quotes taken from Jones et al. (2012).

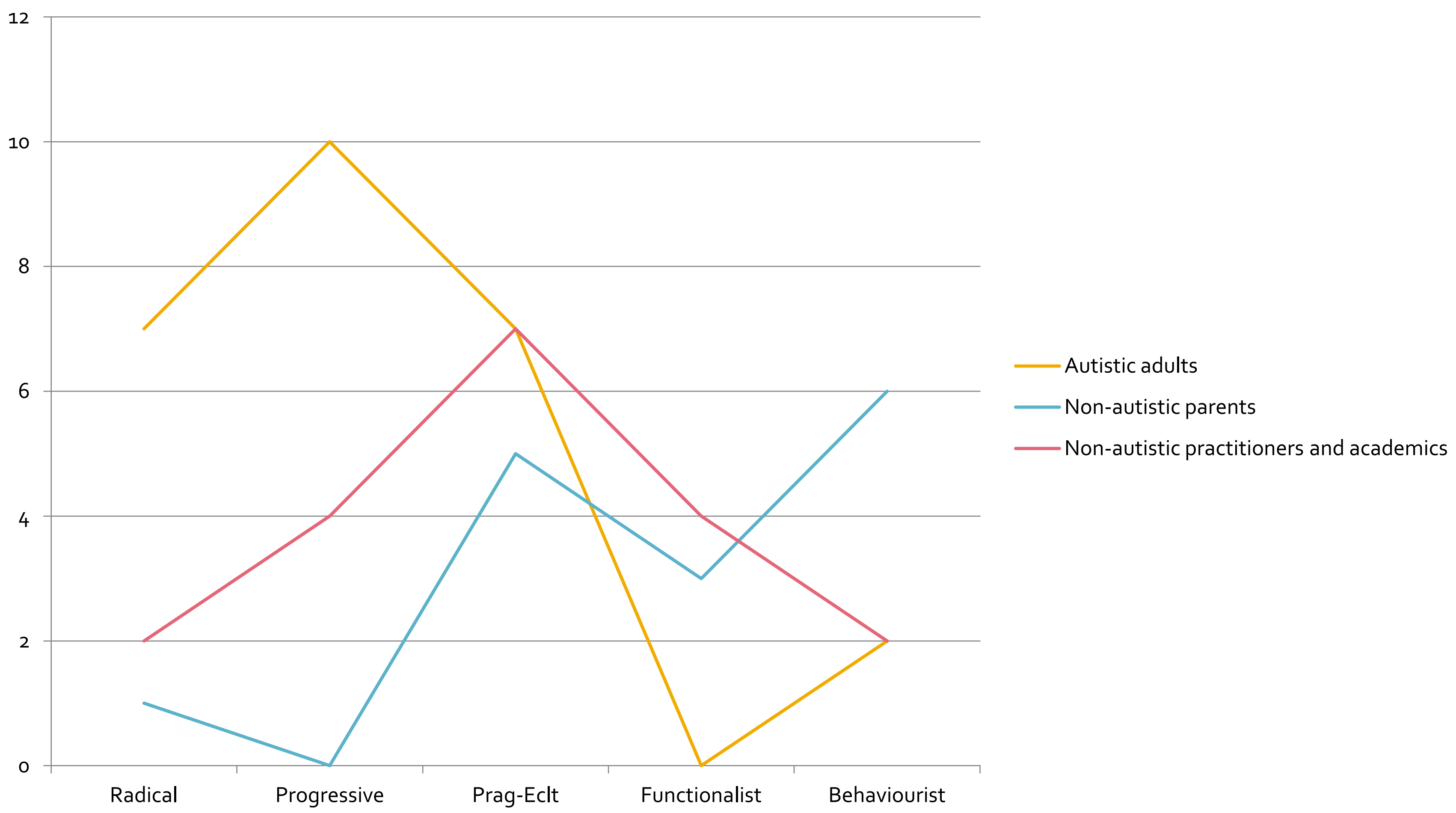
The ‘double empathy problem’

- Building bridges between people of autistic and non-autistic dispositions is not always an easy process.
- The different perceptual worlds of the differently socially (dis)positioned (Milton, 2012b, 2014a, Chown, 2014).
- Empathy problems as a ‘two-way street’ (Sinclair, 1992).
- In this theory, it is not only the autistic person who struggles to read the intentions and motivations of non-autistic people, but the same can also be said in reverse.
- Theory of autistic mind can often leave a great deal to be desired.
- ‘Fork ‘andles’!

Stakeholder perceptions

- Findings from PhD research.
- Significant tensions over a number of issues:
- Celebrating the diversity of learners and not trying to ‘normalise’ them.
- Radical change in society.
- Pupil-led vs. teacher-led activities.
- Social skills training and the appropriateness of behaviour.
- The ‘three-way dispositional problem’!

Spectrum of educational views

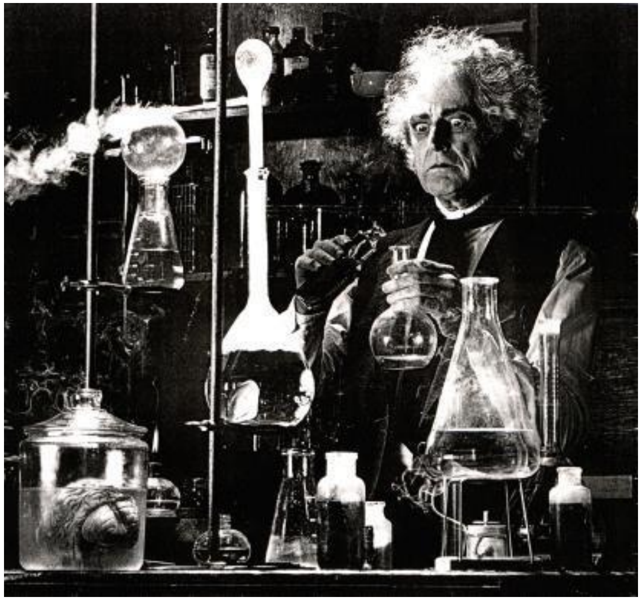


Common ground?

- Not a great deal!
- Against extreme normalisation?
- Enabling environments?
- Building relationships, communication and mutual understanding.

The autistic voice and the production of knowledge

- People on the autism spectrum rarely in the role of researcher, traditionally seen as passive subjects.
- The 'glass sub-heading' (Milton and Bracher, 2013).



Co-production

- “Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours" (New Economics Foundation).
- To what extent is this currently possible?
- To what extent is this ideal taken seriously in service provision or research?

Participatory research

- A range of theoretical and methodological approaches.
- Yet with the main objective of handing power from the researcher to research participants, who are often community members or community-based organisations.
- In participatory research, participants have control over the research agenda, the process and actions taken.
- Most importantly, people themselves are the ones who analyse and reflect on the information generated, in order to obtain the findings and conclusions of the research process.

Emancipatory research

- “By definition emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process, but whether this is achievable is a highly contentious issue.” (Barnes, 2001)

Difficulties in the involvement of autistic people in research

- Autobiographical accounts – representativeness of the ‘high-functioning’? Or not?
- Sampling – diverse breadth of experiences of those on the autistic spectrum.
- Cognitive and linguistic demands may impair full involvement for those with learning disabilities, yet hearing views is important for participation/contribution (Lewis and Porter, 2004).
- Representativeness of peers and familiar adults as proxy informants (Lewis and Porter, 2004).
- Pictures and schedules – not always sure that views reported were the children’s own (Preece and Jordan, 2009).

- Episodic memory and ‘recency’ effect (Jordan and Powell, 1995).
- Questions regarding wishes and aspirations may be meaningless or even threatening (Beresford et al., 2004, cited in Preece and Jordan, 2009).
- Trouble understanding use of language (literal, echolalia, idiosyncratic).
- Preece and Jordan (2009) found that participants were best at identifying preferences regarding concrete objects (something tangible and not vague). Emotions and reasons for liking and disliking others more difficult for participants to answer.

Consent

- Individualised letter explaining the research and an introductory meeting (Preece and Jordan, 2009).
- Ongoing process rather than one-off agreement (Lewis and Porter 2004; Preece and Jordan, 2009).

Recommendations for involving autistic people in research

- Lewis and Porter (2004) suggest the very minimum should be establishing the value of research for those with learning disabilities – how is it useful? Avoiding harm.
- Participants should be able to provide responses to initial analysis and receive feedback from the outcomes of a study (and in an accessible format).
- Observational research where a child had little or no speech. Best included in research by 'being with them' (Preece and Jordan, 2009).

- Accessible outlines of interview questions given in advance. Or time to give a considered response / use of the Internet (Lewis and Porter, 2004).
- Opportunity for use of other mediums – drawing, photography, film – useful ‘aide-memoires’ (Powell and Jordan, 1992, cited in Preece and Jordan, 2009).
- Concrete manipulation – piles of like and dislike. Photographic narratives / scrapbooks (Preece and Jordan, 2009).

Practicalities

- How can controversies be handled ethically?
- Not everyone wishes to be a researcher (although some will), but do want their views heard, understood and utilised to help others.
- Variety of consultation and participatory methods can be used – yet may need to start with small steps.

Are assumptions made by researchers unjustified?

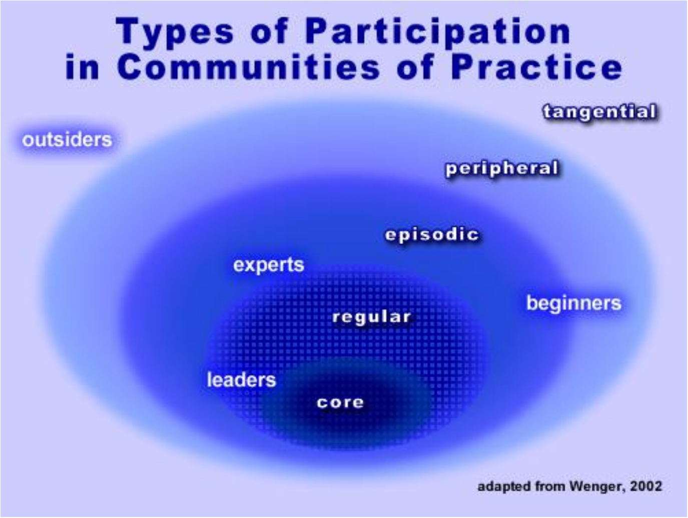
- Repetitive behaviour and obsessions or monotropism, interests and flow states? (Murray et al. 2005, Lawson, 2010, Milton, 2012a, McDonnell and Milton, 2014)?
- Theory of mind deficit or the double empathy problem (Milton, 2012b)?
- The capacity of less verbal autistic people to participate.

Collaboration

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Avoiding tokenism…
- "…place the voices and perspectives of self-advocates at the centre of the autism conversation, as we can speak with unique legitimacy and voice about our own lives." (Ne'eman, 2011).

Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.
- The Ask autism project.
- The Theorising Autism Project.
- The Autonomy journal.
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- The Participatory Autism Research Centre (PARC) at London South Bank University.
- The National Autism Project (NAP) and Westminster Commission.



adapted from Wenger, 2002

Conclusion

- “Traditional methods of consulting and working in partnership may not always be effective, and new avenues for connection may need to be sought, however when collaborative ventures are pursued, and when people on the autism spectrum feel included and empowered, the ability to live as one chooses greatly increases.” (Milton, 2014b).

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